



# SPINAL COURIER

**SPINAL CORD**  
COMMISSION

Vol. 2 No. 4

July, 1991

## Two Hundred Attend Second Annual Conference

The Second Annual Arkansas State Spinal Cord Commission Conference was attended by 208 professionals, clients and their families. Entitled "Living with Spinal Cord Injuries in the 90's" the conference was held on June 14, 1991 at the Holiday Inn West in Little Rock.

The conference program offered a variety of subjects from which the attendees could choose. Topics included current SCI research efforts in Arkansas, recreation opportunities, bladder management and employment to mention a few. The Sexual Expression - Communication and Experimentation section was very well attended, as usual.

**See Conference on page 3.**



Attendees filled up the main conference room this year and the hall as well.

## Living Will Gives Arkansans More Input into Own Medical Care

Arkansans, who have an incurable or irreversible condition, can now direct their attending physician to withhold or withdraw treatment that prolongs the process of dying if they are unable to make decisions about their treatment. These rights are provided by the Arkansas Rights of the Terminally Ill or Permanently Unconscious Act.

In order to access these rights for yourself, a legal document called a living will must be completed while you can still make decisions for yourself. A living will tells

others of your wish to refuse treatment that you feel is excessive or inappropriate if you should become unable to express your wishes in the future.

The University Hospital of Arkansas and Blue Cross and Blue Shield of Arkansas has put together a living will for Arkansans to use in making their wishes known.

This brochure was developed under the direction of the Medical Ethics Committee, University of Arkansas for Medical Sciences.

Copies of the living will brochure are available at no charge from:

University Hospital of Arkansas  
4301 West Markham Street  
Slot 728  
Little Rock, AR 72205

or

Blue Cross & Blue Shield  
of Arkansas  
P.O. Box 2181  
Little Rock, AR 72203

## SPINAL COURIER

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lyzed Veterans of America, Spinal  
Cord Injury Education and Training  
Foundation.

## BUCKLE UP!

### *Sports Anyone?*

The March/April, 1991 issue of Sports and Spokes magazine printed a comprehensive list (page 96) of national sports associations for wheelchair individuals. The list includes each association's complete address and telephone number and contact person.

Although the list is too long to reproduce here, we will be happy to mail you a copy. Send your request in care of the SPINAL COURIER and we'll pass it along to the Resource and Education Center. The Center will then send you a copy.

### **Wheelchair Vans in England**

A new service has been started to provide self-service rental vans for wheelchair travelers arriving at Heathrow and Gatwick Airports in England. The vans are equipped with hydraulic tail elevators, wheelchair securing gear and safety harness. Price varies with size of the vehicle and time of the year. For more information contact: Wheelchair travel, 1 Johnson Green, Guildford, Surrey GU2 6XS, England; (483) 39661.

## SPINAL COURIER Letters

Questions • Suggestions • Directions • Answers

SPINAL COURIER Letters is a new column devoted to readers' concerns in any area related to their spinal cord impairment.

Have a problem you think we might be able to help solve? Got a helpful suggestion you think that others would be interested in? Need direction on how to find certain information?

Send us a Letter!

Put the combined strength of over 2500 SPINAL COURIER readers to work for you! If the ASSCC staff can't find an answer for you, perhaps one of our readers can.

### **Wheelchairs Wear Out Carpet?**

Dear Editor:

I recently applied for an apartment and was told the accessible units didn't have carpet because wheelchairs destroy carpet. I've been in a wheelchair for 20 years and this is news to me. I'd like to know if anyone has any facts to back that statement up or if anyone else has had a similar experience.

Pearl Hunt  
Rogers, Arkansas

Well, how about it readers? Has anyone else heard of this? Any carpet dealers out there who would like to comment? Would anyone like to tell us if their wheelchair seems to wear out their carpet faster or not?

We'll print the letters we receive in the next newsletter. Until then Pearl, tread lightly!

Editor

### **AUTO INSURANCE FOR SPINAL CORD IMPAIRED DRIVERS**

**Dear Editor:** I have a spinal cord impairment and have found difficulty in getting auto insurance at reasonable rates. Some companies add a premium to their usual policies for impaired drivers. Is this legal? Kyle Sharp, N. Little Rock

**Dear Kyle:** One of the many forms of discrimination faced by persons with spinal cord impairment is in the area of automobile insurance. While some people with spinal cord impairment are completely unable to obtain auto insurance, others who have been successful in doing so have been faced with insurance premiums which can range from 1/3 to 1/2 more than their non-disabled peers, with comparable vehicles and driving records.

One remedy may lie in a request to the state Insurance Department to investigate the possibility of discrimination based solely on disability. Forms for requesting assistance may be obtained by calling Paul Fray at 371-1813 or by writing to the following address:

Arkansas Insurance Department  
Consumer Services Division  
400 University Tower Building  
Little Rock, AR 72204

One of the questions a driver will be asked is if he/she has a satisfactory driving record for the previous five year period. If the answer to this question is "yes", and you feel that you have been discriminated against based solely on your disability, you may be entitled to a refund on excessive premiums you have paid.

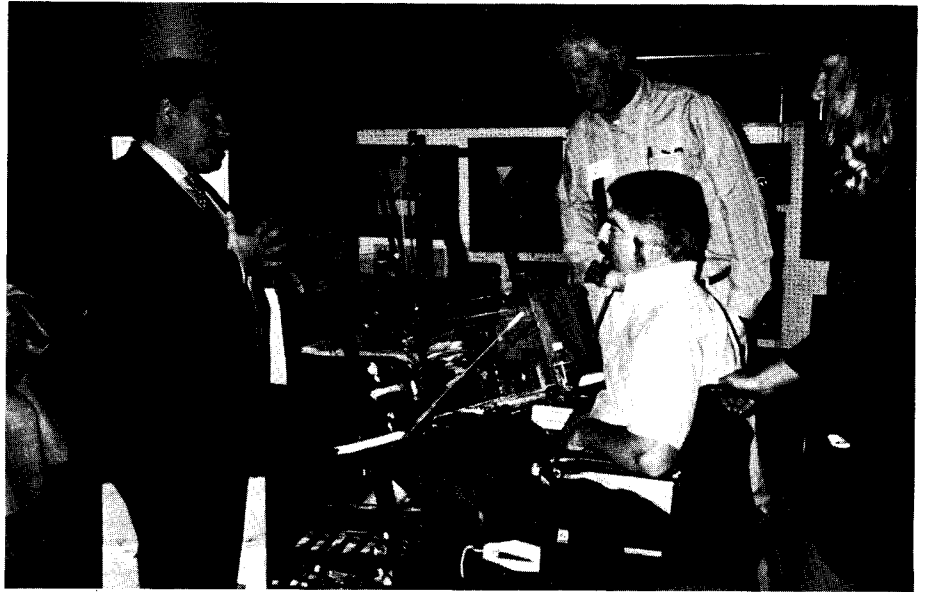
*Thanks to Glennis and Dee Sharp and Adrian Horton. Editor*

## Conference from page 1.

Attendees received updated information about spinal cord injury, enjoyed lunch along with entertainment, renewed old friendships and struck up new acquaintances.

If you couldn't make it to this year's conference, mark your calendar now to attend the next conference in June, 1992. Plans are being made now to make next year's conference better than ever.

Photos on this page spotlight some of the activities of the 1991 conference. See anyone you know?



Dr. Garcia-Rill chats with artist Dale Tabor as Benny Beals admires Dale's work.



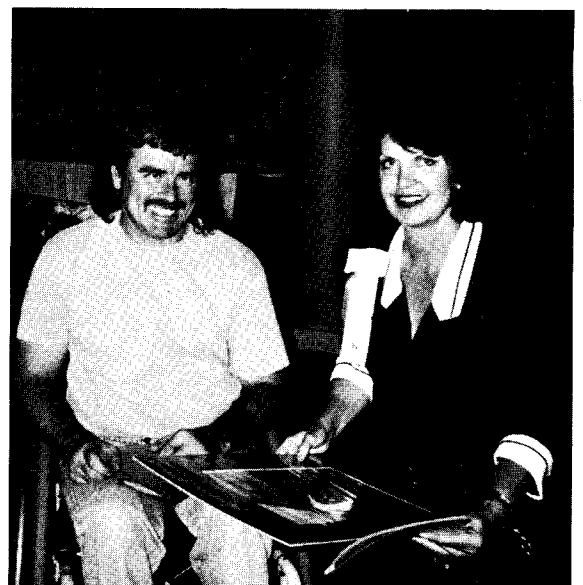
Dr. Souheaver talks about chronic pain.



Dr. Mark Jumper, Bettie Tapp and Eddie Still relax after lunch.



Leo Johnson, Evelyn Wainright and Alfred Wood share a happy moment.



Marty Johnson and Health Educator, Ann Whitehead.

# RESEARCH AND SPINAL CORD INJURY

by  
Shirley McCluer, M.D.  
ASSCC Medical Director

Anyone who has a spinal cord injury or knows someone who has a spinal cord injury is hopeful that someday a cure will be found to eliminate the permanent effects of this devastating condition. In recent years the news media often have dramatic headlines which suggest that "cures" have occurred and everyone gets all excited, but all too often it turns out to be a false alarm or the significance of the findings has been grossly exaggerated. Research discoveries do not happen overnight. They require many years of well designed experiments and careful analysis of the results. When new drugs show promise in animal experiments, there is a long, complicated process to prove that the drug is effective in humans and safe (that is, it doesn't cause harmful side effects that are worse than the benefits).

In order to understand the significance of some of the newer treatments, it is necessary to have a basic knowledge of what happens to the spinal cord following injury. There is still much that we don't know, but a great deal has been learned in the past 20 years from both animal and human experiments.

For example, it has been known for many years that even in very severe injuries where no recovery occurs, the spinal cord is rarely completely cut in two. In fact, in some permanent injuries, the spinal cord may look normal when it is seen at surgery. However, from animal experiments we have learned that several events take place following moderate (incomplete) injury:

1. Some nerve cells are destroyed immediately. At the present time we have no way to replace these dead nerve cells.

2. Some nerve cells are temporarily damaged, but with care to prevent further injury they will recover without any further treatment.

3. Some nerve cells are further damaged by the swelling and other chemical changes that occur over the first few days following injury.

A major problem is that we have no test that will tell us immediately after injury how many of the nerve cells are in each of these categories in a specific patient! Most of the research has been aimed at better understanding of No. 3 above and trying to find some way to prevent this delayed nerve damage. All of the studies described below fit into this category of treatment.

The most recent "miracle cure" reported in the news media (last week of June, 1991) was a report of a study done in 1986-87 comparing a series of 16 patients using an experimental drug (called GM-1) with 18 patients given a placebo (inactive drug). In order to keep everyone completely fair and honest, no one knew which patient received which drug until every patient had been studied for a full year. The drug was started within 3 days after injury and continued daily for 3 to 4 weeks. Both groups were treated alike except for the drug. Some patients in both groups got better, some patients in both groups did not get better, and one patient in each group had complete recovery. However it was felt that the group treated with the experimental drug had more patients with more improvement than the non-treated group.

Fortunately there were no significant side effects or complications in the group receiving the experi-



mental drug. The conclusion was "although this study suggest that GM-1 is safe to administer in SCI and enhances the recovery of neurological function after one year, a larger study must be conducted before GM-1 is considered safe and efficacious in treating spinal cord injury."

Unfortunately GM-1 is still experimental and has not been approved by the FDA for use on humans except in studies such as this and it may be several years before it is approved. But because no harmful effects were noted and it seems to be helpful, obviously tests will be continued.

In contrast, consider what happened in studies with steroids which also were effective in animal experiments. Several SCI centers participated in a study using a standardized dosage of steroids immediately after injury and followed for 1 year. These studies were reported in 1985 concluding that steroids should not be used because no benefits were demonstrated and there were more complications in the treated group. In fact, the study was stopped early because of the number of complications.

A new study was started using a completely different dosage and timing for the treatment. In the spring of 1990 the results were announced with much publicity. At the end of 1 year the patients who had received treatment within 8 hours after injury and who had an incomplete injury showed more improvement than the untreated

**See Research on page 8.**

# JANE SMITH HONORED!

Jane Smith, Founder and former Chairperson of the Arkansas State Spinal Cord Commission was honored by the Governor's Office, Office of Volunteerism and KARK Channel 4 with a 1991 Community Service Award. She was one of 8 recipients honored at a gala event in the Grand Ballroom of the Excelsior Hotel on June 18th, 1991. Mrs. Smith received her award in recognition of her many years of work on behalf of people with spinal cord injuries and her accomplishments in the development of resources for these individuals.

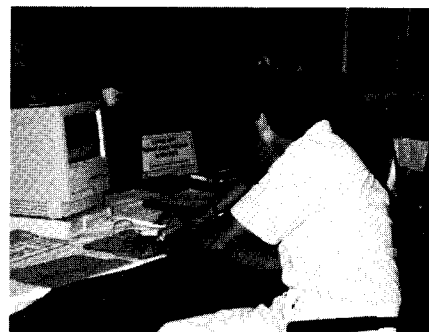
Beginning her plight when her mother sustained a spinal cord injury in 1956, Mrs. Smith worked tirelessly for many years to access medical care and rehabilitation for Arkansans with spinal cord injuries. She has impacted the lives of many individuals whom she has

helped personally or who have been assisted by programs such as the Spinal Cord Commission and Baptist Rehabilitation Institute, as she was integral in the development of both.

In receiving her award, Mrs Smith stated that she was honored but that she accepted it on behalf of numerous individuals who had helped the cause, including her husband Maurice Smith, Steve Flanigan M.D. and Harold Thomas, who were all present for the ceremony.

A donation of \$500 has been made to the Education and Resource Center of The Arkansas State Spinal Cord Commission in honor of 1991 Community Service Award Recipient Jane Smith.

Congratulations, Mrs. Smith, it was a well deserved honor!



Connie Carroll of the ASSCC staff assists a conference attendee to search the Resource Center's databases.

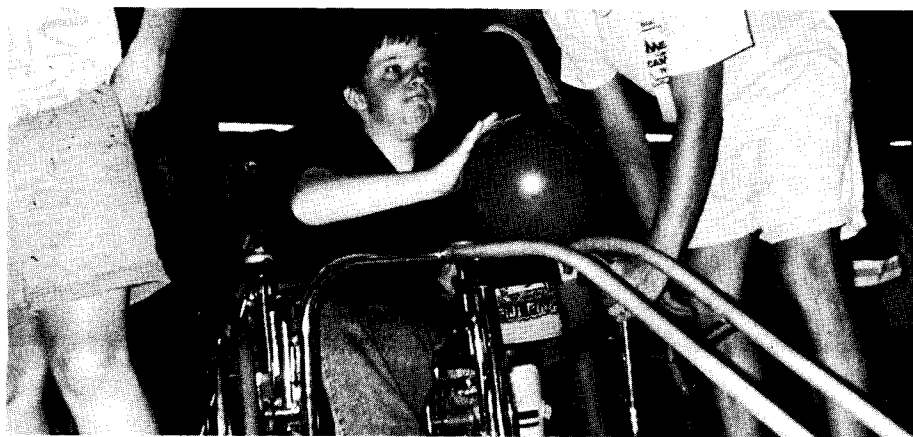
## ASSCC Resource Center Popular with Conference Attendees

Quite a few attendees at the ASSCC SCI Conference stopped by the Resource Center booth to acquaint themselves with the Center's materials. Representative books, articles, and video and sound tapes were on display to give an indication of the type of materials available for loan. The Center's Macintosh computer was also set up for people to browse through the Center's resources.

The Hyper-able-data database was put to immediate use by clients, vendors and professionals to check on the price or availability of certain equipment. The Computerized listing of the Center's resources provided quick answers to the question, "Do you have a copy of \_\_\_\_\_?"

ASSCC continues to recruit volunteers to assist in the Center. So far Robert Neasley, Gwen Winston and Denise Greening have volunteered their services. Volunteers will help catalog and file resources, enter data into the computer, complete resource searches, answer the phone and mail requests.

If you are interested in working one or two afternoons a day or month, please contact Cheryl Vines at 324-1624 or Tom Farley at 324-9620. The Center's grand opening is scheduled for September.



Joseph O'Lien lines up a strike during spina bifida camp this year.

## 1991 Spina Bifida Camp

We just completed another successful year of Spina Bifida Camp. A total of 68 children attended the two weeks of camp and a great time was had by all.

Activities included: swimming, bowling, canoeing, arts and crafts, games, a trip to Pinnacle Mountain, a visit by the Rollin' Razorbacks and much more.

This camping experience is quite unique in that it is very enjoyable for the children as well as educational in that it teaches them independence and also about their disability.

The children attending Camp attend at no cost to their family. Camp is conducted in cooperation with Med Camps and Camp Aldersgate and is funded by ASSCC.

# Thank You Letter from B.C. Cobb

June 25, 1991

Dear Friends,

Mill joins me in this genuine expression of appreciation for the delightful and enjoyable dinner party hosted by the Director and Staff, and the Case Management Personnel on June 13. This party was a terrific culmination to over four years of the most satisfying and gratifying service in which I ever hope to engage. The "Outstanding Performance Award" and the poem "Reflections" are proudly displayed in our home.

To the Commission Members, The Executive Director and Staff, I thank you for the opportunity I have been afforded to serve as a Case Manager for and with you. To the Case Management Supervisor, my fellow Case Managers, and to the Administrative Personnel throughout ASSCC, I offer my most sincere thanks for the outstanding cooperation and support always available to me. I know that you will never lose sight of your challenge and service to those far less fortunate than most. I will always consider myself one of you and will remain dedicated to your purpose.

Be assured that your concern for the welfare of your clients and your dedication to that total purpose has instilled in each of you a degree of professionalism that far exceeds that evidenced by other human service organizations with which I have been involved or have studied. Despite a chronic shortage of case management monies and other trying conditions, each of you has employed your own ingenuity in providing care and comfort to those so desperately in need. This is a true mark of your dedication and ability.

And. . . , to all clients being served who are the basis for ASSCC's existence, I appreciate each of you. Few, if any, handicaps could match yours. You are the braver lot! Remember that ASSCC serves without obligation and with nothing but your well-being in focus. To each of you, I extend my best wishes and my continued love and support.

To all, I thank you for my opportunity to have served.

Sincerely,  
B. C. Cobb  
Former ASSCC Case Manager

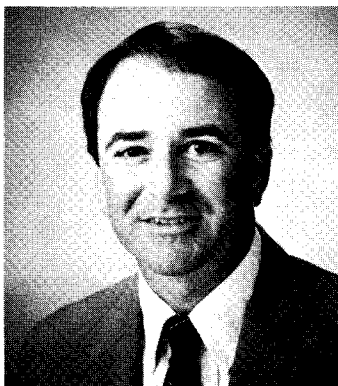


Isaiah White gets a hand from his Dad unhooking the catfish he caught at the April, 26th fishing derby at MacArthur Park in Little Rock.

## 78th General Assembly Enacts Tax Legislation of Interest to the Disabled

by

David Worlow, CPA



The recently concluded 78th General Assembly enacted one bill of benefit to disabled Arkansas citizens and considered another before tabling it for further study.

Act 708 provides for a \$500 itemized deduction for taxpayers who maintain, support and care for a totally and permanently disabled child in the taxpayer's home. The deduc-

tion is not subject to the 2% of AGI (Adjusted Gross Income) reduction.

Under Act 708, a child may be either a natural or adopted child. "Disabled" means a child who is unable to engage in any substantial gainful activity due to his disability. The disability must have lasted or be expected to last at least twelve months, or be expected to result in death if less than twelve months. Act 708 is effective for tax years 1991 and later. A physician is required to certify the disability.

The legislature also considered House Bill 1832 before tabling it for further study. H.B. 1832 would provide for a tax credit of \$500 for any taxpayer who maintains and cares for a disabled spouse in his home. H. B. 1832 defines "disabled" essentially the same as is found in Act 708, except that H. B. 1832 is uncertain at this time.

Note that a tax credit differs from a tax deduction in that a credit results in an actual reduction of income tax, whereas a deduction merely reduces taxable income.

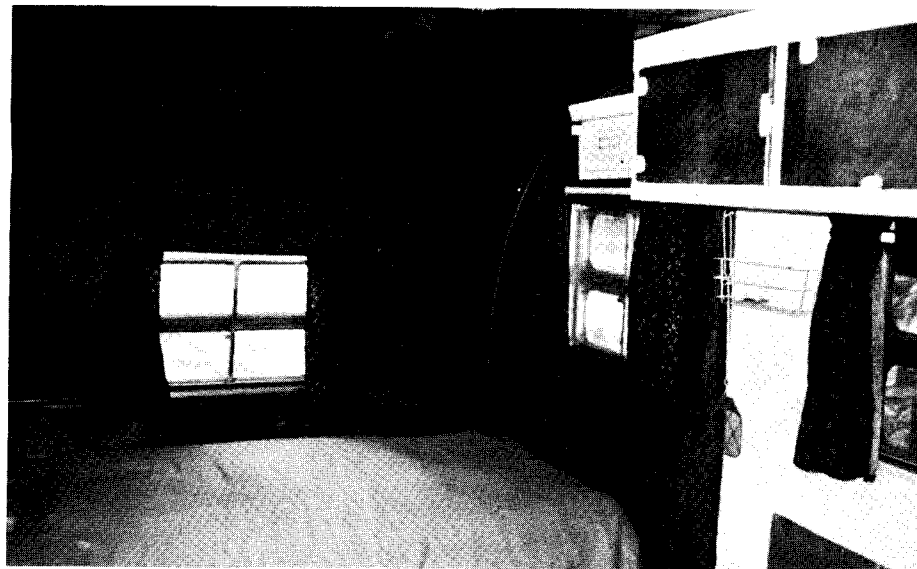
# Making Camping Accessible

Of the more than 200,000 persons with spinal cord injuries in this country, many have been and would again like to be campers. While non-disabled persons have many choices about where they would like to go, the facilities they would like to use and the activities available to them, those who must

make a statement as a group to bring about more accessibility in campgrounds.

Sam Johnson of Kerrville, TX, who was paralyzed in an accident in 1950 was one of the co-founders of HTC. He attributes a lot of his recovery to the fact that

since he was injured. His wife, son and grandchildren headed for the Little Red River for some fishing. Billy watched as the family fished. There was no tent and there were no facilities so the plan was to stay one night and return home. Janie had prepared a roll-away bed for her husband and opened it "under the stars." Everyone enjoyed the experience so much that the decision was unanimous to stay a second night.



The inside of Doug's camper allows room for a wheelchair to maneuver.

depend on wheelchairs are limited in their choices. Sue Conner, president of the Post-Polio Support Group Foundation told a group in April, "My biggest pet peeve is for a (park) official to say there is no demand or need to be accessible because no one with a disability ever uses our facility. Have they never thought that maybe it is because the facility is inaccessible to a person with a disability?"

Voices of the disabled are being heard and organizations formed to bring about changes. The Handicapped Travel Club, founded in 1972, has rallies much like those sponsored by the Good Sam Club. There is a lot of food, fun, music and fellowship among the campers. It is not a support group although members do get a lot of support and encouragements from each other. They also learn new ways to do things and are able to

he had an RV and could travel. "It takes your mind off your troubles. It's amazing to go to a rally and see what people deal with."

In Arkansas, avid campers have found various ways to overcome inaccessibility. Billy Fletcher recently went on his first campout

Doug Grant, also a quadriplegic, was interested in camping. His mother and her husband had a camper, but it was not large enough for him and his wheelchair, even if he could get in the door. Then they had an idea. A small used camper was purchased and stripped inside. A low bed was built across one end and the rest of the space left unfurnished (see photo left) to allow him room to get around. With the door widened (see photo below) and a portable ramp, Doug's own camper became a way he could enjoy the outdoor life. Doug's mother admits it is inconvenient to take two vehicles so they can pull both trailers, but having the opportunity to enjoy camping again is well worth the trouble. They are able to stay three days before returning home for Doug's personal care.

Other persons with spinal cord injuries report adapting vans for  
**See Camping on page 8.**



Doug Grant exits from his accessible camper - note the wide door and portable ramp.



## THE SIDEWALK

By  
Douglas Blann

On the cement walk that stretches from my front porch through my yard,  
I'm imprisoned by its edges, because its surface is hard,  
Where the smoothness of the cement stops, rise the walls of my cell,  
Today I am a hostage, but only you and I can tell.

### Camping from page 7.

camping out. If a camper is fortunate enough to find a campground that is level and has accessible bathrooms, the trip can be much more enjoyable, but if he is prepared for inaccessibility, he will still be able to camp with his own provisions. More and more, persons in wheelchairs are realizing they can participate in outdoor activities, even camping.

The Arkansas Department of Parks and Tourism has a brochure with information on accessible camping areas in the state. To receive a copy, call 682-7777. The address of the Handicapped Travel Club is: 6 N. Louis St., Mt. Prospect, IL. 60056. Accent on Living, Box 700, Bloomington, IL. 61702 (309-378-2961) is a company that produces a magazine, by the same name, and acts as a clearinghouse of information for handicapped

persons and can put callers in touch with local services. Referrals are free unless a computer search is required. The Automobile Association of America also publishes a paperback book called the Handicapped Driver's Mobility Guide which lists manufacturers of hand controls and tips for selecting the best and most appropriate equipment. Contact your local AAA office.

If you are a camper and would like to share your experiences and ideas with others through this newsletter, send pictures and information to the editor.



Printed on recycled paper.

### Research from page 4.

group. However, if given more than 8 hours after injury there was no benefit.

Almost immediately after this report was announced, most U.S. Trauma centers began to treat all new injuries with the recommended dosage. The key difference between this study and the one with GM-1 is that the steroid used was already approved and was readily available in hospitals so it could be ordered by any physician.

Future studies will undoubtedly evaluate patients using both steroids and GM-1 to see if they give more benefit than either one alone, or if they react negatively together so that only one or the other should be used.

These studies are only intended to help future new injuries, not those who are already paralyzed.

In the next SPINAL COURIER, other benefits from research will be reviewed.

**PROGRESS IS SLOW,  
BUT IT IS STILL PROGRESS!!**

## SPINAL COURIER

Arkansas State Spinal Cord Commission  
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Little Rock, AR 72202

### Commission Members:

Grover Evans - Jonesboro  
Sloan Lessley - Calico Rock  
Russell Patton - Jonesboro (Chair)  
Glennis Sharp - North Little Rock  
Sheila Galbraith Bronfman - Little Rock

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